

牵我手，
Hold my hand,

每个明天一起走。
We will meet each tomorrow together.

无论如何，
It doesn't matter how we do it,

或遇欢笑或忧愁，
Sad or laughing out loud,

你和我牵手一起走。
Hand in hand, together we go.

生命如歌
Life is a
SONG



生命如歌
Life is a
SONG ▶▶▶

Li Ka Shing Foundation
[Heart of Gold] National Hospice Service Program
李嘉诚基金会【人间有情】全国宁养医疗服务计划

*Seize the day,
Make the most of life.*



愿留住最后的时光，
画出完美的句点，
再一次拥有生命的光辉。





前言

在“爱”面前，文字有时候显得苍白无力，而图片能够更真实地再现当时的情境；又因着每个人的人生阅历不同，对所发生的事情也有不同的解读，透过图片更能让人用自己的语言诠释“爱”的内涵。

李嘉诚基金会『人间有情』全国宁养医疗服务计划在中国实施已经有十一个年头，这支服务于贫困晚期癌症患者的专业队伍不断扩大，服务范围及服务人数更是日益提高。这其中鲜为人知的感人事迹处处可见，“爱”的种子传播到了每一个阳光照不到的角落。每一个生命都弥足珍贵，每一段生命的历程都如曲子般可歌可颂，无论是高潮还是低谷，无论是热烈还是平淡，都是“生命之歌”不可或缺的音符。正因如此，贯穿本书自始至终的就是那一首首让人时常吟唱的歌。

本画册旨在把宁养服务的内容真实地表现出来，让更多的社会大众了解什么是宁养，让有需要的群体可以及时寻求帮助，让热心的人士能够参与奉献社会的行列。因版面限制，画册所能讲述的内容极为有限，更多的故事每天都在遍布中国大地的三十一家宁养院上演，宁养人将穷年累月，恪守优质的服务承诺。

李嘉诚基金会
汕头大学医学院顾问
全国宁养医疗服务计划项目负责人
罗敏洁

2010年6月



Cancer Patients Have Contributed To Society And We Hope That
The Last Part Of Their Life Journey Can Be Less Agonizing And
More Dignified.

..... Li Ka-shing

癌症患者曾对社会做出过贡献，
希望他们在离开世界之前得以尽量减少痛苦，
让他们在最后的日子里，也能活得有尊严。

——李嘉诚

INTRODUCTION To Hospice CARE

认识宁养护理



第一篇
CHAPTER
ONE

定义

Definition

在中世纪时代，用来作朝圣者或旅行者中途休息、重新补足体力的驿站。

Hospice is a concept of caring derived from medieval times, symbolizing a place where travelers and pilgrims could find rest and comfort.

在现代，是一种组织化的医护方案，注重团队精神照顾，为临终病人及其家属提供缓解性及支持性的照顾。

The contemporary Hospice offers a comprehensive, collaborative, and multi-disciplinary program to care for patients and families facing a life terminal illness.

特点与内涵

Characteristic features

H-Hospitality	亲切、爱心
O-Organized Care	团队照顾
S-Symptom Control	症状控制
P-Psychological Support	精神支持
I-Individualized Care	依个别情况照顾
C-Communication	沟通、互动
E-Education	教育

目的

Objectives

- 1、辅导癌症等疾病末期病患与家属接受临终事实。
- 2、达成身、心、灵完整之关怀医治。
- 3、减轻或消除癌末病患身体疼痛、不适症状或心理压力。
- 4、消除病患与家属之怨怼，享受人生最后亲情。
- 5、尊重病患权利，关心其生命品质。
- 6、使病患安详走完人生最后一程。
- 7、使家属敢于面对病患死亡，使生死两相安。

1. Communicating bad news
2. Addressing physical, psychological and spiritual needs
3. Providing relief to a terminally ill person by managing his pain, symptom and emotions
4. Helping to solve or to mitigate interpersonal problems
5. Valuing the patient's autonomy and quality of life
6. Ensuring a peaceful and comforting end of life's journey
7. Helping families to cope with death and find peace with the death of a loved one

李嘉诚基金会 「人间有情」全国宁养医疗服务计划

由李嘉诚基金会赞助，现时于国内25个省、市、自治区的31个大中城市设立31家宁养院，免费为贫困晚期癌症患者提供镇痛治疗、护理指导、心理辅导等方面家居服务的医疗慈善项目。

服务对象 贫困的晚期癌症患者

服务宗旨 以人为本，全人服务，提高晚期癌症患者的生活质量

服务方式 家居服务，咨询服务，门诊服务

服务内容 镇痛治疗、护理指导、心理辅导、哀伤辅导，宁养知识宣教

项目管理机构 李嘉诚基金会『人间有情』全国宁养医疗服务计划办公室设立在汕头大学医学院，负责协调各宁养院具体运作和指导工作，并通过互联网管理各宁养院的日常工作和各种信息等

网址 www.hospice.com.cn

Li Ka Shing Foundation [Heart of Gold] National Hospice Service Program

Funded by Li Ka Shing Foundation, the Hospice Unites are distributed in 31 cities of 25 provinces in China, providing free home-based holistic care for patients with advanced cancer.

Target patients Economically disadvantaged patients with advanced cancer

Mission Patient-centered holistic care; improve quality of life for patients with advanced cancer

Types of service Free home visits, out-patient and counseling services

Scope of service Pain relief, nursing care, psychological and bereavement support provide continuous care for the patient and family

Management Program office based at Shantou University Medical College facilitates and oversees the operation of the national program, also acts as a coordinating and resource center

Website www.lksf.org (in English)
www.hospice.com.cn (in Chinese)

舒适温馨的环境

Comfortable environment

■ 广东汕头 Shantou Guangdong



咨询室
Counseling room



候诊大厅
Waiting area

Meeting 遇见你 
YOU today can be different

今天可以不一样

第二篇
CHAPTER
TWO 

因为遇见你 我有了生命的盼望

You have restored
my will to live

■上海 Shanghai

芳芳，后腹膜纤维瘤病

Fang-fang, retroperitoneal fibromatosis

二十一岁，正是女人如鲜花般灿烂的年纪，正是喜欢扮靓，喜欢各种社交活动，爱唱爱跳的年纪。二十一岁的芳芳，正值青春年华，未来看似一片光明。那时的芳芳工作于上海共青森林公园的一个大型中国饭店，收入也比较高。然而，1993年的一个夏天，左腿的一阵剧痛开始了芳芳人生的噩梦。这看似平常的腿痛却引发了毁灭性的后果——肆无忌惮滋长的癌细胞，无常的心理情绪变化。接下来的16年无时无刻不被这些噩梦所缠绕。

Women in their early 20s are at the height of youth. The decade for fashion experimentation, socialization, ultimately enjoying the freedom of youth. Fang-fang, 21, had a bright future ahead of her. At that time, she held a relatively high paying job in an upscale chinese hotel at the Shanghai Gongqing Forest Park. However, during the summer of 1993, a painful left leg injury began a terrifying ordeal that affected the rest of her life. What initially seemed like a simple leg pain soared into overwhelmingly long-termed hospital stays. The cancer's irrepressible growth and its associated emotional challenges took control for the next 16 years of her life.

十六年前，芳芳被确诊为后腹膜纤维瘤病，医生预估存活期只有两年——短暂得让人不敢想象的数字。一个原本乐观，外向的女孩变得极度怨恨，她不明白为什么这种事情会发生在她身上。芳芳开始无休止的抱怨，她憎恨这个世界，这个让她遭遇苦难的世界。

Sixteen years ago, the doctors estimated she only had two years left to live, which was too short to comprehend. Originally an optimistic and friendly girl, Fang-fang became insufferable. She complained daily and hated the world for her misfortunes not understanding why this was happening to her.

由于剧痛，一直卧床不起的芳芳住进了医院。医生为她开了杜冷丁，这是一种很容易上瘾的止痛药，芳芳每天要注射两次杜冷丁，短短的一个星期就染上了药瘾，如果不服药就变得神志不清。药性发作的时候，芳芳会胡乱抓住周围的锐器反复地刮自己的脸颊企图抵制药瘾，甚至一个小小的发夹都会成为她自残的工具，所以一切稍有危险性的东西都要远离她。很快地，芳芳对杜冷丁的依赖性增加至每两个小时一剂，她的父母每天24小时都要守在床边，轮班为她注射药品。受到药物的严重影响，有时候仅为了求得多次注射，芳芳就对着父母大发脾气。

During her hospitalization, Fang-fang was prescribed Demerol due to severe pains that immobilized her. After only a week of Demerol at the rate of two shots a day, Fang-fang became addicted. Without the drug, she had to be kept clear of hazardous materials while struggling to

maintain her sanity. Even simple items like hairclips became tools for self-mutilation. She would repeatedly scratch her face to cope with the withdrawals. Eventually, her needs increased to one shot every two hours which meant her parents were confined to her hospital bed in twelve hour shifts so to administer the shots. Fang-fang's behavior to her parents was plagued with temper tantrums until she could get the next fix.

由于注射了大量的杜冷丁，芳芳出院的时候腿上的肌肉已经坚硬、退化，只好往脸上注射。终于，她的家人决定送她去康复中心。做出这个决定并不容易，因为康复中心的治疗费用需要5,000元，这对于刚刚支付了2次手术费用和3年的住院治疗费用的家庭来说是非常昂贵的，芳芳和她的家人不仅面临精神上的折磨，更要面临严重的经济困难。虽然治疗的过程只有12天，但却是非常痛苦的，因她已经注射了整整10,000剂杜冷丁，值得庆幸的是，芳芳恢复得很快，连康复中心的医护人员也觉得难以置信。

By the time she checked out of the hospital, Fang-fang's dosage had become so high, her leg muscles hardened and deteriorated. As a last resort, her injections were taken in the face. It was then that the family turned to a rehabilitation center for help. Not only was the therapy mentally grueling, but financially demanding as well. The entire process would cost up to 5,000 RMB. The family savings were wiped out during the 3 years of hospital fees and 2 surgeries. Surprisingly, her agonizing rehab process was successfully completed in merely twelve days. Even the rehabilitation staff could hardly believe the fast recovery from her 10,000 shot addiction.

“一两百米之外你就可以听到她的叫声！”这是爸爸在谈到芳芳开始在康复中心的日子所说的。起初，看到女儿由于得不到药物而被折磨得不成人样，父母非常不忍，偷偷地藏了一些杜冷丁，瞒着医生为她注射。那时候，芳芳甚至自残，所以她的指甲都被剪得短短，但她痛不欲生，又把自己的手伸入口中。不忍心看到女儿这样伤害自己，已经67岁的父亲把自己的手给她咬。多年以后芳芳感激地说：“我真的很感谢我的父母。”

“You could hear her from 100, even 200 meters away!” as her father described the screams

during the first days of rehab. Initially, the parents secretly stashed away some Demerol for Fang-fang since they couldn't bear to see her reactions to the withdrawal symptoms. Her nails were trimmed short to prevent any self disfigurements. Unable to scratch her face, she sank her teeth into her own hands. Unable to watch his daughter harm herself, fang's 67 year-old father would offer his own hand to his daughter instead. Many years later, Fang-fang gratefully remembered and said, “I am tremendously thankful for my parents.”

芳芳的病情好转不到一个月，她又开始发烧，右腿肿胀。医生检查之后，决定在不施行任何麻醉措施的情况下在芳芳的右腿划开一刀。从此，芳芳的伤口需要敷上厚厚的一层敷料，才能防止体液的流出。

After nearly a month of being in good shape, Fang-fang began to have fever and a swelling in her right thigh. This prompted her to return to the hospital where she previously sought consult. There, the doctors made an incision into her thigh without any anesthetic. She was sent home and advised to put a thick dressing on the wound to absorb fluids that would come out of it.

过了一段时间，芳芳感到双腿疼痛加剧。于是，医生为她进行了检查并替换敷料，这时，体液从伤口处喷射而出。喷出的体液中夹杂着一些像咸菜叶的不明物。医生怀疑这并非肿瘤物质，建议进行检验。果真如医生所料，检验结果表明这些不明物体为咸菜叶。原来，芳芳的内脏都被癌细胞所侵蚀，以至于把食物都挤出了大腿的皮肤外。

After a few days, Fang-fang complained of increasing pain in her legs. This made her decide to return to her doctors for check-up and a subsequent change of wound dressing. When the dressing was removed, some fluid began spurting out of the wound at high pressure. In the fluid was a particle that looked like a piece of a pickled vegetable. The doctor suspected that this strange particle was part of a tumor, and suggested that it be examined. However, when the result came out, it turned out that the particle was really a piece of a pickled vegetable! On further investigation, it was found out that the tumor she had before, had displaced her intestine to the skin of her thigh. This was followed by rupturing of the intestine and the skin of the thigh, and consequent spilling of food particles from there.

虽然到此时为止，芳芳已经患病6年，经历了各种病状，但却从没见过这种状况。她被医生们称为：“食物从腿上出来的人”。不久，像芝麻、蔬菜等其它食物也从伤口处涌了出来。只要她一摄入富含纤维的物质，就会从大腿出来。她甚至连米饭都不敢吃，因为一颗小小的米粒都让她很难受。结果，她只能吃莲藕粉，用这种糊状的东西替代其它食物。这一吃就是整整一年，导致她身体极度虚弱，牙齿也因此而脱落。

芳芳与她的宠物
Fang-fang and her pet



Having experienced all types of illness for the past six years, this incident was totally unheard of to Fang-fang. She got really shocked and scared about this incident. To the doctors, she became known as “the patient who had food particles coming out of her legs”. In the following days, it was also reported that other food particles came out of her legs like sesame and other vegetables. Whenever she ate something high in fiber, it would come straight out of her legs. This led her to be scared of eating porridge for she thought that the small pieces of rice would hurt her. As a result, she resorted to eating lotus root powder for one entire year. This would substitute for all of her favorite foods. She however became so weak, and her teeth started to loosen and fall off.

芳芳又再住院3年，她的家人轮流日夜守着她。在芳芳患病的前九年里，她的父母从来没有安稳地睡过觉，但他们毫无怨言。对他们来说，照顾女儿就是父母天职。照顾的工作虽然很艰辛，但只要女儿能活着就比什么都好。而同时，芳芳的妈妈腿上发现了一个肿瘤，让这个本来就灾难重重的家庭雪上加霜。但芳芳的妈妈并不把自己当病人看待，女儿在她心目中是第一位，她害怕自己会死，但不是因为怕死，而是担心孩子的爸爸一个人无法承担照顾女儿的重任。幸运的是，在亲人的帮助下，妈妈接受了化疗，肿瘤之苦痛暂时被控制住。芳芳的爸爸坚守着乐观的精神，竭尽全力撑起了这个家，承担了所有的事情——买菜、洗衣服、各种家务……这些都是他以前从没做过的。

Fang-fang was hospitalized for another three years. Her family watched over her day and night. In the first 9 years of illness, her parents never complained about the lack of a peaceful night's sleep. To them, taking care of their daughter was a natural part of their parental responsibilities. Although difficult, it was well worth in having their daughter be alive. It became more difficult when the mother found a tumor growing in her leg. However, she remained calm and refused to see herself as a patient. In her heart, her daughter is first. The mother's only fear was that her death would mean the father then be left to shoulder the heavy burden as their daughter's sole caretaker. Thankfully, the mother received chemotherapy with their extended family's assistance. The tumor is now in remission. As for the father, he remains optimistic. He will do everything he can for his family even things he had never done before... grocery shopping, laundry, or anything he is capable of helping.

遇见你今天可以不一样 Meeting You Today Can Be Different

更糟的是，就在这时芳芳的哥哥出了车祸，一只眼睛被撞瞎了。但是家里的经济情况让他不但无法接受治疗，还要在附近的一家大型超市继续工作，维持这个有着四位病号的家庭的经济收入。

To make matters worse, Fang-fang's older brother was involved in a car accident around the same time and went blind in one eye. Unable to afford visual medical treatments, the brother continued to work at a large nearby supermarket. He needed to bring in money for his family as every member is suffering from some sort of ailment.

到目前为止，芳芳得病卧床已经十余年。除了经常性的胃肠清洁，依靠着吗啡药片，芳芳的情况基本“稳定”。他们没有医疗保险，一分一毫都靠自己支付，这个家庭负担着沉重的经济压力。

By now, Fang-fang had lived with this illness for 10 years. This condition also entailed constant attention to her intestinal issues which was only kept stable with morphine tablets. Without medical insurance, the family was under a huge financial strain to support these prescriptions.

幸运地，经过介绍，上海宁养院开始了对芳芳的服务。宁养院得知芳芳喜欢看电影，特地为她联系了附近的DVD店，让芳芳有看不完的电影。这不仅转移了芳芳对疾病的注意力，也让她与宁养院的关系更加密切。

Fortunately, a doctor referred them to the National Hospice Service Program of Li Ka Shing Foundation. With time, Fang-fang began to

电脑连接着芳芳与外面的世界
Computer connects Fang-fang with the outside world



trust the hospice workers. When asked what she wanted to do, Fang-fang discussed her love for movies. The hospice worker soon contacted a DVD store nearby and brought her numerous movies. This not only distracted her from the illness, but also began building a relationship between the patient and the hospice staffs.

多年的病痛，芳芳失去了过去朋友的联系，惧怕被评头论足以及外型的改变也使她不肯与外界接触。宁养院的义工袁女士为此将自己的手提电脑借给芳芳，芳芳开始了学习的路程。如今她能帮父母上网购买家中所需物品，再一次，她觉得她被认定是家中有用的一份子。

At the same time, Fang-fang found it difficult to reconnect with past friends. They won't understand her ordeals and feared their judgment. In an effort to reconnect Fang-fang with the real world she had lost, hospice volunteer, Ms. Yuan, gave her a spare laptop from the office. Fang-fang learned how to use a computer, how to type, and browse the internet. She can now be a part of the world community again. In fact, as an avid user of the shopping and auction websites, she even makes purchases for the family. She has redefined and renewed her role in the family to be someone fully capable of helping her parents as they grow old.

电脑所带来的益处不仅仅停留在对家庭的帮助。另一位义工林女士，她是一家中国地方医学期刊的通讯员，她帮助芳芳学习写作，投稿。芳芳的处女作面世了，作品描述的就是她的亲身经历，她还获得了稿费。在学校的时候，芳芳就经常在作文比赛中获得一、二等奖，因此，写作对她来说一点也不陌生。了解了这个情况，林女士就请芳芳帮忙编辑报纸文章，做校对，写评论，还提供题材让芳芳去创作。芳芳借助电脑进行网络搜查撰写文章，如今几乎每个星期五都可以在这份地方报刊上看到芳芳的作品，她俨然成了一名专栏作家。通过写作，芳芳不仅把她的见识带给世界，也让她获得满足感，重新找到生命的意义。

The benefits of the computer, however, are not limited to just assisting Fang-fang's family. Ms. Lin, a volunteer is also a reporter for a local Chinese medical newspaper. She asked Fang-fang to write for the paper. She first began with a piece about her own personal experiences with this

illness. She was even compensated for the work! Fang-fang is no stranger to writing. While still in school, she won first and second prizes in writing competitions. Knowing this, the reporter asked her to edit some of the newspaper's articles, so Fang-fang could proofread and write comments. Additionally, Ms. Lin would provide topics allowing Fang-fang to research online and type up the article on the computer. Nowadays, Fang-fang's articles are published nearly every Friday by the local Chinese newspaper. She is a genuine columnist. Her contribution to the world by writing has also given her a sense of fulfillment and a renewed meaning in life.

在宁养院的帮助下，芳芳的疼痛得到了缓解，学会了利用网络资源，加上家人的支持，芳芳不再是一个绝望的癌症患者。也许她仍然无法恢复自由行动，但她的精神已经得到释放了，在十楼的房间里过着与世交流的生活。

Under the hospice assistance, her pain was alleviated, she learned to access internet's resources. Along with her family's undying support and determination, Fang-fang is no longer a hopeless cancer patient. Though she may still be physically confined to her room, she has been psychologically unshackled from her conditions. Now lives a fulfilling life from her 10th floor apartment.

图文：林思妤 By Lillian Lin

爸爸、妈妈和义工朋友
一起为芳芳庆生
The parents and volunteer
celebrate for Fang-fang's
birthday



水中的小船是梁先生的家
Mr. Liang lives on the boat

仿佛依稀，在水一方。
旧事已过，都变成新。

On the other side of the river, a life is renewed.

■广西 Guangxi

梁先生，鼻咽癌
Mr. Liang, nasopharyngeal cancer



求医的道路是如此艰难，
但宁养院的医护人员不畏困难，坚持上门探访

There is no way for Mr. Liang
to go to the doctors, but there
are ways for hospice doctors to
come to Mr. Liang



急切的期盼
Anticipating the
coming visit



认真的聆听
Listening attentively



中秋前夕，医护人员和义工一起来到梁先生的家，大家一起动手，把小船整理得焕然一新，让梁先生感受到了久违的家庭温暖。

Mid-autumn festival eve, the boat was tidied up and decorated by the hospice staff and volunteers to bring Mr. Liang a home-like happiness.

生活的阴霾烟消云散，梁先生脸上展露出开心的笑容，对生活有了新的盼望。

No more cloudy days for Mr. Liang! Hope in his life is renewed.
Now he can happily smile again.



今天是我 happiest 的日子

it's the happiest day in my life

■新疆 Xinjiang

小红第一次走进教室，这一天她年满 18岁。
On her 18th birthday, Xiaohong was able to
walk into a classroom for the first time in her life.



郭小红，肝癌

Guo Xiaohong, liver cancer

郭小红3岁的时候，狠心的父母就把她抛弃并从此消失，小红再也没听到任何父母的消息。有人说，天底下最无私、最伟大的爱是母爱，可小红没有尝过这样的滋味。在她的心里，外公外婆就是她最亲的家人。

When Guo Xiaohong was three years old, she was abandoned by her parents and never heard from them again. Xiaohong had not received any parental love. Her grandparents are her closest relatives.

小红的外公外婆和他们的四个孩子决定收养她。但一家7口人的经济来源就是外公和外婆每月加起来不到600元的工资。那个时候，对这老两口来说，让一家人吃饱穿暖就是天大的事情。在这种情况下，小红上学的事根本就无暇顾及。

Xiaohong's grandparents and their four children decided to care for her. However, a monthly income of 600 yuan was all they could earn to support the whole family of seven. Under such circumstances, getting enough food on the table was a problem. How would they afford to send Xiaohong to school?

几年里，小红的外公和大舅先后因病去世，家里的顶梁柱一下子折断了。现在，小红和外婆生活在51平方米的小房子里。她们的生活来源就是外婆每月500元的退休工资，扣除150元的房租和100多元的取暖费之后，已经所剩无几。然而，噩运就像挥之不去、令人厌烦的苍蝇一样纠缠着这个家庭，更大的不幸悄然降临——小红被确诊为肝癌晚期。“总想着，我老了老了，红红是个伴儿。这一下，天跟塌了一样。”外婆说。



小红看上去就像一名
真正的学生
Xiaohong looks no different
from other students

Unfortunately, several years later, Xiaohong's grandfather and his oldest son passed away, leaving Xiaohong and her grandmother living alone in a room only 51 square meters large. After deducting 250 yuan in rent and utility fees, their total income was only 250 yuan monthly. To make matters worse, Xiaohong was diagnosed with a terminal case of liver cancer. “I would always reflect upon the later years of my life and how Honghong would be my companion, but now everything is over,” said her grandmother.

“郭小红”这三个字是小红最熟悉的，那是小的时候外公教给她的。看着街道社区里同龄的孩子都在上学，多少次，想去上学的话到了嘴边，又咽了回去。懂事的小红不愿意给这个家添麻烦。仅有一次，她悄悄跟宁养义工说：“真想有一天，能坐在明亮的教室里，听老师讲课，当一回真正的学生，哪怕只能听一堂课也好”。了解到这个情况，宁养院进行了精心安排，让小红来到了乌鲁木齐第三小学。

When Xiaohong was little, her grandfather taught her how to write her name. “Guo Xiaohong,” the characters of her name, were the only words she could recognize. Xiaohong often suppressed her urges to attend school because she understood that her family could not afford the tuition. She only revealed this fantasy once, secretly mentioning to a hospice volunteer, “I wish that for just one day, I could sit in a well-lit classroom, listen to the teacher give a lesson, and be a real student. Even if it were only for one class. That would be nice.” Understanding Xiaohong's wish, the hospice of Affiliated Tumor Hospital of Xinjiang Medical University made an arrangement with the Third Primary School of Urumchi for Xiaohong to attend school.

上午10点整，本该是早读课的时间，但因为小红的到来，早读课改成了见面会。“红红姐姐，欢迎加入我们班集体”，“红红姐姐，祝你身体健康”，小红刚进教室的不自然，渐渐地被孩子们真诚热情的话语轻轻化解、消散。上午10点10分，广播里传来全校集合的音乐，这本来是出早操的时间，但为了小红，今天特意改为了升国旗仪式，因为这是小红的第一次，也是仅有的一次升国旗仪式。上午10点40分，小红坐在教室里开始了生平的第一节课。也许对许多同学而言，这不过是再平常不过的一节课；而对小红来说，却是她梦寐以求的一节课。虽然她听不太懂老师在讲什么，也还不理解课文的内容，但这些并不重要；重要的是可以听老师上课，可以像其他同学一样上课了。这一刻，小红看上就像一名真正的学生。

While 10:00 A.M. is normally “Reading Time”, there was a change of plans. They used this time instead to meet with Xiaohong. “Welcome to our class, Honghong”, the class greeted warmly, “We wish you the best of health.” While Xiaohong initially felt nervous and uncomfortable, she was surrounded on all sides by friendly, smiling classmates. Her discomfort faded and she was excited. The national flag raising ceremony was moved to 10:10 A.M. so that Xiaohong could be present, as this was her first chance and probably last chance to attend such an event. At 10:40 A.M., Xiaohong attended class for the first time in her life. For many students, this was just like any other class, but for Xiaohong, this was a life-long dream. Although she could not follow the teacher's lesson or understand the contents of the book, to her, it did not matter. Engaging with her teacher and interacting with classmates, for once, Xiaohong was no different from other students.



老师为这名特殊的学生上课
A special class is arranged for Xiaohong

11点25分，教室里响起了歌曲“爱的奉献”的旋律。曲声中，教室的门被缓缓打开，一辆精心装饰的小餐车被推了进来，车上放着蛋糕，这是专门为小红准备的生日蛋糕！餐车在小红的面前停了下来，接过切好的蛋糕和学校师生为她募集的500元爱心捐款，红红的泪水再也抑制不住，不断滴落在蛋糕上……“孩子们，把你们的礼物送给红红吧。”吴老师的话音未落，拿着自己礼物的孩子们，纷纷从座位上走上前来，把红红团团围住。

“红红姐姐，这是我们班同学为你叠的100只千纸鹤……”

“红红姐姐，这是我送你的幸运星，祝你生日快乐……”

“红红姐姐，送你一支笔，希望你好好学习……”

“红红姐姐，这是我的存钱罐，里面是我存的零花钱，你拿它买点营养品吧……”

小红满脸泪水，反复地念叨：“谢谢老师，谢谢同学们……”。她接着说：“这么多的人，我记不住你们的名字，可是我知道，没有你们，我的心愿就没法实现。无论我今后如何，我永远都记得，今天是我 happiest 的日子！”

At 11:25 A.M., Xiaohong's classmates began to play the song, *Dedication For Love*, and rolled in a lunch cart they had decorated for her. On the lunch cart, there was a cake for Xiaohong. Accepting the cake and the money collected by students and faculty of the school, Xiaohong could not help but cry, shedding tears on the cake…… “You can give Xiaohong your gifts now,” said the teacher. Immediately, Honghong was surrounded by the students.

“Honghong, this is one hundred paper cranes made by the whole student body…”

“Honghong, these are some lucky stars for you. Happy birthday!”

“Honghong, this is a pen for you. I hope you do well in your studies! Study hard!”

“Honghong, this is a money box with all my pocket money. Take it with you and buy some good food…” Xiaohong was so moved that all she could do was repeat, “Thank you! Thank you, everybody…” she went on to say further, “Although I can't remember all of your names, I know in my heart that my dream could not have come true without all of you. No matter what happens to me, I will always remember today as the happiest day of my life.”

文：傅翔龙 By Xiang-long Fu

同学们为小红庆祝生日
Birthday celebration





W

Walk With Me

Every Day Is A Brand New Day

一起走

拥抱新的每一天

第三篇
CHAPTER
THREE

有爱就有神奇

张开双手拥抱新的每一天

■云南 Yunnan

When there is love, there is mirade,
open your heart and embrace
each new day



常女士，淋巴瘤
Ms. Chang, lymphoma

破旧的家
Run-down housing



护士到家里探访
Home visit



Walk With Me Every Day Is A Brand New Day 一起走拥抱新的每一天

一起走柵抱新的每一天 Walk With Me Every Day Is A Brand New Day

全新的一天，全新的世界，全新的一切
Brand new day, brand new world,
everything is brand new

关心备至 Concerned



亲如家人 Like families



Walk With Me Every Day Is A Brand New Day 一起走柵抱新的每一天

喜逐颜开
Satisfied



在这里， 她找到了宁静的避风港

This is where she found her tranquil harbor

■福建 Fujian

陈女士，鼻咽癌 Ms. Chen, nasopharyngeal cancer

一个艰辛痛苦的女人，20年前曾因家庭暴力致颅脑外伤而晕倒在田野中。这让她不得不以离婚来结束这种非人的生活。她离家之后，年仅四岁的儿子瞒着父亲，独自一人跌跌撞撞，找到了母亲。为了照顾年幼的儿子，她违心地回到夫家。几年后，只因生了一个女儿，她又多次遭受丈夫的毒打，这让她不得不再次逃亡。

She is a woman who has suffered far more than one can bear. Twenty years ago, she was the victim to family violence resulting in brain injuries that caused her to pass out in the middle of a field. Consequently, she decided to file for a divorce. When she left, her four-year-old son went looking for her without telling his father. Ms. Chen, despite her ill feelings toward her ex-husband, decided to move back with him so she could take care of her son. Several years later, she was repeatedly beaten by her husband because she gave birth to a girl. She needed to escape again.

委屈、痛苦
Grievance & anguish





医生检查身体
Physical examination

2008年2月，噩运再一次降临，鼻咽癌的诊断临到她身上。肉体上的疼痛，加上心里的重重委屈与悲痛，她痛彻心扉，但却哭诉无门。

In February 2008, Ms. Chen was struck with misfortune again. She was diagnosed with nasopharyngeal cancer. Physical pain added to spiritual bitterness. She was overwhelmed with grief, but she had no one to turn to.

终于，她找到了福建宁养院。当医护人员初次上门探访的时候，她痛哭出声，人生第一次，她得以把一生所遭受的痛苦释放出来。宁养院的医生不仅帮她缓解了癌痛，更为她带来心理上的慰藉，让心灵的枷锁得以卸下。

Fortunately, Ms. Chen found the Fujian Hospice Unit. When the doctors first came to visit her, she wept in grief. She had finally found a place to express her deep-seated frustrations. The doctors not only relieved her physical pains, but also comforted her and allowed her to vent her emotions.



喜乐的泪水
Tears of joy

Walk With Me Every Day Is A Brand New Day 一起走拥抱新的每一天



风不能,雨不能,不能隔绝
宁养人的爱

Nor wind nor rain will stop the hospice from loving

■云南 Yunnan

期盼
Expectant



雾天
Foggy day



问路
Asking for directions

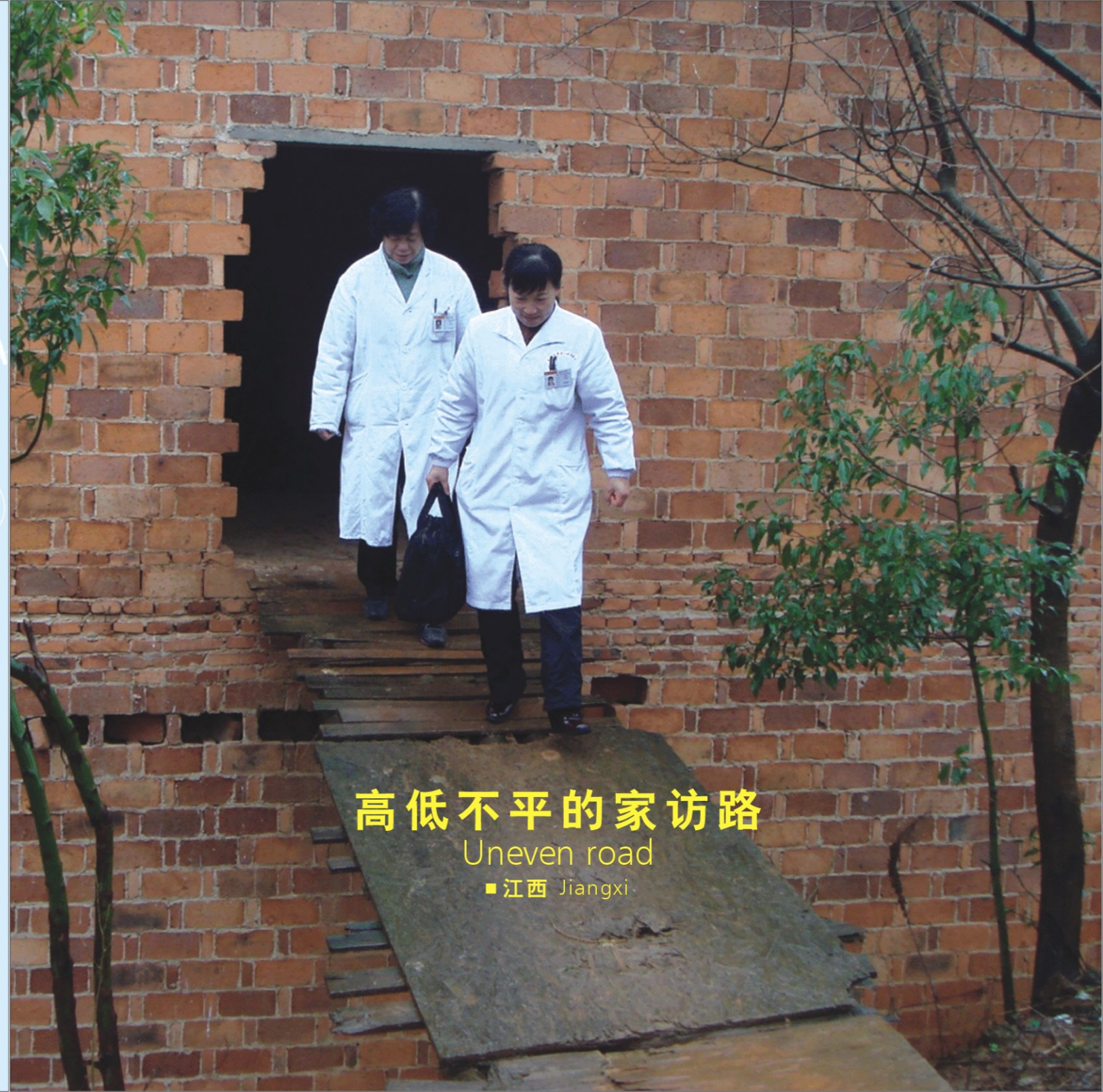
一起走，拥抱新的每一天 Walk With Me Every Day Is A Brand New Day



泥泞滂沱，车走如行船
Muddy road



大雨倾盆，挡不住宁养人的脚步，
他们的心牵挂着山里的病人
Marching in the heavy rain



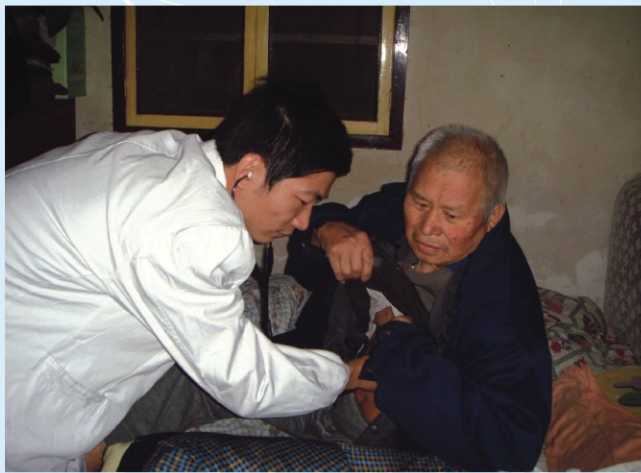
高低不平的家访路
Uneven road
■ 江西 Jiangxi

一起走拥抱新的每一天 Walk With Me Every Day Is A Brand New Day



精心护理 Nursing care

领导关心
Dedicated leadership



专心检查 Thorough check-ups

Walk With Me Every Day Is A Brand New Day 一起走拥抱新的每一天



社会教育
Community education



世界宁养日
World Hospice Day



你是我的亲密的朋友
You Are My Dear Friend

第 四 篇
CHAPTER
FOUR



周伯伯实现了最后的心愿： 看一看秋水广场

Mr. Zhou's dream
of visiting the
Qiushui park comes true

■ 江西 Jiangxi



消除怨怼，心里平安

Mediating disputes, a psychological balance

■湖南 Hunan



张先生, 口咽癌

Mr. Zhang, oropharynx cancer

张爷爷是一位不幸的人，15年前一场车祸使他失去右腿，从此只能靠撑小板凳走路。车祸后，患者的人生彻底改变了，他对肇事者一直心存怨恨，耿耿于怀，两家的关系也因此破裂。

Mr. Zhang is an unfortunate man. Fifteen years ago, he lost his right leg in a car accident. Since then, he gets around by using a small stool as a cane. After the car crash, Zhang's life had changed completely and he resented and hated the driver who hit him. The relation between the two families was almost irreparable.

屋漏偏逢连夜雨，本来已经被贫困所折磨的老人又罹患了口咽癌。老人来到宁养院寻求帮助，经过全面了解情况之后，宁养院的医护人员不仅帮助张爷爷解除了因癌症所引起的疼痛，还帮助抚平他心里的不平。经过多次的尝试，宁养院医护人员成功地消除了这段恩怨。肇事者来到老人面前，恳求宽恕，终于，老人说出了“我原谅你”四个字，顷刻间，十五年的气愤，十五年的怨恨烟消云散。经过宁养院的这一番帮助，张爷爷最终获得了心灵上的平安。

To make matters worse, Zhang's family was already plagued with financial difficulties when they discovered that Zhang had oropharynx cancer. After the hospice staff became aware of the situation, they tried to help him. Hospice workers not only helped Zhang to alleviate the physical pain caused by his cancer, but also tried to reduce his psychological burden. After many attempts to find the perpetrator and bring him to Zhang, the hospice was eventually successful. The man who hit Zhang stood before him and begged for forgiveness. A large burden, 15 years of resentment and hatred, was lifted from Zhang's shoulders with three words, "I forgive you." After a great deal of counseling, Zhang's mind was finally at ease.

一边是肺癌晚期的父亲，
一边是软骨肉瘤的儿子；

A father with lung cancer,
a son with chondrosarcoma;

**他们躺在床上心急如焚，
家人却全然束手无策...**

They lay on the bed worrying about their
conditions. The family feels powerless...

■ 甘肃 Gansu

义工陪伴
Keeping company



医生和家属开家庭会议
Family meeting

拒绝死神的诱惑

Resisting death

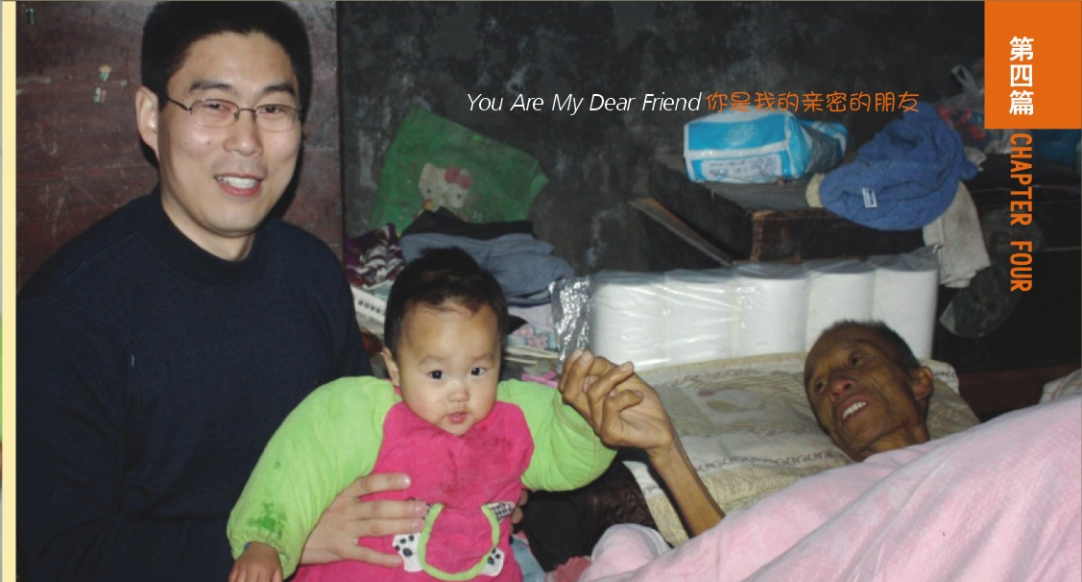
■ 河南 Henan



张老伯的手腕上两度自杀的伤口触目惊心
Two wrist wounds from attempted suicides



张老伯的孙女和医生成了好朋友
The doctor befriends Mr. Zhang's granddaughter



满足的微笑来自宁养的服务
Fortunate to receive Hospice services, Mr. Zhang smiles happily

张老伯，食管癌患者

Mr. Zhang, esophageal cancer

年幼时曾被家人遗弃，营养不良、身患皮肤病，生命奄奄一息，后被人捡到并收养。晚期身患绝症，遭受痛苦折磨，家庭贫困，曾两度自杀。

Abandoned at an early age and inflicted with cancer in his old age, Zhang could no longer bear the pain of everyday life and attempted to commit suicide.



吕女士，直肠癌

Ms. Lü, rectal cancer ■ 吉林 Jilin

医护人员为二老带来儿女般的关怀

Medical professionals treat the old couple like their own son and daughter

刘先生，肺癌

Mr. Liu, lung cancer ■ 吉林 Jilin

小孙女用陪伴为外公拭去面颊的泪水，纯洁的童声抚慰外公心灵的伤痛。

Liu's granddaughter accompanies him at the bedside, wiping away his tears.
Her gentle voice comforts him.





As Loving As Families

老人家的心愿

与亲如家人的宁养工作人员合照





By 就在这里陪你到最后 Your Side To The End

第 五 篇
CHAPTER
FIVE

Even Deep In The Mountains, One
Can Find Families 大山深处有人家



The best of times and the most beautiful
of places, is right here, right now,
because of you.

最好的时刻，最美的地方，
就是现在，就在这里，
因这里有你，有你的同在。

■ 云南 Yunnan

杨先生，腹膜后恶性肿瘤

Mr. Yang, malignant neoplasm
of retroperitoneum



by your side to the end 就在这里陪你到最后

开心了! Now he is happy!



身体检查 Physical examination

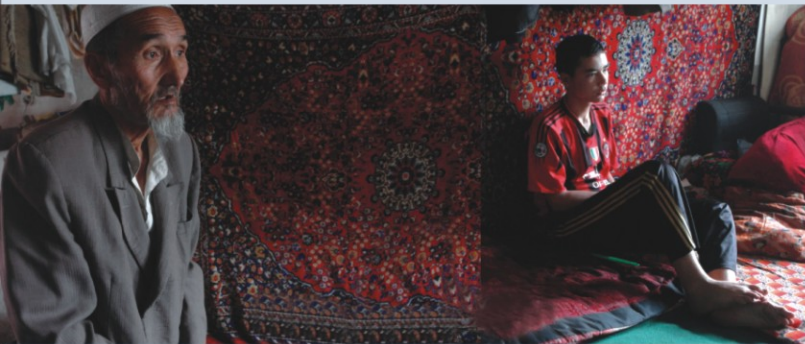


就在这里陪你到最后 by your side to the end

努尔泥沙，维族，宫颈癌

Ms. Nuernisha, Uygur ethnic group, cervical carcinoma

■新疆 Xinjiang



担忧、无助的家人
Helpless families



疼痛难忍 Suffering

by your side to the end 就在这里陪你到最后



舒服了! Now she is comfortable!

王先生的故事

A story of Mr. Chen ■ 云南 Yunnan

陈先生，肝癌

Mr. Chen, liver cancer

虽然罹患肝癌的并不是杨赛书，但这疾病却让她遭受了极大的痛苦。事实上，她所遭受的苦难比真正得了肝癌的丈夫要沉重得多。在决定嫁给越南华侨陈先生为妻的时候，杨赛书就已经知道她甭想过上阔太的舒适生活。陈先生在9岁的时候不小心踩到了地雷管，从此失去左臂。年少残疾的陈先生很好地适应了单手的生活。他开了一家摩托车修理店，生活虽不优越，但也算过得去。一家四口过着简单的生活，两个儿子也过得无忧无虑。与芒市的许多家庭相比，陈先生一家算是过得很好的。有一次，大儿子的眼睛需要动手术，他甚至还能专程到广东治疗，并在珠海过了一个小假期。现在，这样的日子已经恍如隔世。

Although Sai-shu Yang is not the one with the liver cancer, yet her share of hardships and adversities may be more as the caregiver to her husband, who is diagnosed with the cancer. She married the Vietnamese-Chinese Mr. Chen knowing it would not be a life of luxury. When Chen was only nine years old, he stumbled across a detonator, which took his left arm. Handicapped so early in life, Chen adapted remarkably well and has since become proficient in



using his remaining arm to complete daily tasks. Although not of a privileged life, Chen has made a decent living managing a motorcycle repair shop. His family of four lived a comfortable, modest life. Chen's two sons enjoyed life's simple pleasures. Compared with many other families in Mangshi, Chen's family can be considered one of the more fortunate. When Chen's older son needed eye surgery, his father brought him to Guangdong for treatment as well as enjoyed a short vacation in Zhuhai City. Now, those days seemed a lifetime away.

全神贯注 Listening





患者的母亲也得了脑萎缩
Chen's mother who suffered from dementia

2006年6月份，陈先生一家简单的幸福生活出现了急剧的转变。由于胃部不适，陈先生到医院照了X光。诊断结果为晚期肝癌，医生只把这消息告诉陈先生的妻子。杨赛书还记得刚听到这个坏消息的时候，她震惊得站都站不稳，更不知道如何去面对住在隔壁病房的丈夫。经过医生的一番鼓励，杨赛书最终才有力气离开医生的办公室，来到丈夫身边。然而，杨赛书始终无法把疾病的真相告诉丈夫。无论丈夫怎么问，杨赛书就是没勇气把真相告诉丈夫。不可避免的，陈先生还是从一位亲戚的口中得知了自己的病情。杨赛书说当丈夫得知诊断结果之后表现得无比的勇敢，他继续担当着这个家庭的重任。他卖了摩托车修理店，得到20,000元，并用这20,000元到云南昆明肿瘤医院接受免疫治疗。然而，一个疗程的花费就需10,000元，他们只得又借了20,000元，而日常的生活来源只能依靠手足的慷慨周济。

In June 2006, the Chen family's simple and fortunate life took a catastrophic turn for the worse. Experiencing discomfort in his stomach area, Chen went to the doctor for an X-ray. The doctor then privately informed Yang that her husband has cancer of the liver. Yang recalled her shock as she was told of her husband's diagnosis. She was unable to stand and face her husband in the next room. Only after much encouragement from the doctor was she finally able to leave his office and face her husband. Yet even at his side, or at his constant enquiries, Yang found no courage to break the awful news to him. Inevitably, Chen actually discovered the truth from a relative. Yang says that Chen was incredibly brave even after knowing the diagnosis. He continued to shoulder the responsibilities as head of the household. He sold his shares in the motorcycle repair shop for 20,000 RMB and used the money to undergo immunotherapy at the Yunnan Tumor Hospital in Kunming. With each treatment course costing over 10,000 RMB, Chen was forced to take out a 20,000 RMB loan and relied heavily on the generosity of his siblings to support the family's basic needs.

借来的钱很快就用光了，陈先生不得已停止治疗。在停止治疗而又还没遇到宁养院的这段时间，是陈先生最不堪回首的一段记忆。肿瘤越来越大，难以忍受的疼痛常常侵蚀着他；仅有的收入是政府每月约100元的救助，这点钱不仅要维持陈先生一家四口的生活，还要赡养患有脑萎缩的母亲。自2007年，陈先生母亲的疾病持续恶化，甚至连自己的身体需求都无法照顾。杨赛书担当起照顾丈夫和婆婆的任务，虽然亲戚也给予一些援助，但三餐还是无法饱足，给丈夫的止痛药更是远远不够。一贴小小的吗啡贴剂的价格对这个收入微薄的家庭来说简直就是天文数字。陈先生只得省着用药，一贴只能维持72小时的吗啡，他却贴了四、五天。后来，他们再也没有能力购买任何药品。现在，通过宁养院的帮助，陈先生在最后的日子里总算能够不再被疼痛所折磨。陈先生说如果没有宁养院的帮助，他就没有力气活到现在。因为用了吗啡贴剂，他不再感到疼痛；加上宁养院医护人员所给予的咨询和帮助，即使活着的日子已经无多，却使他重新获得生活的意志。

Chen's loan quickly depleted. He had no choice but to cease the treatments. In Chen's memory, the period that followed and before finding the hospice service was the most impoverished and needing moment. As the tumor grew, Chen lived in a constant state of unbearable pain. The family's only income was approximately 100 RMB/month in government aid. Not only did this have to sustain Chen, Yang, and their two children, but also Chen's mother who suffered from cerebral atrophy and lived with them. By 2007, her ailment progressed to the point that she could no longer take care of her own bodily functions. Yang was left with the challenge of caring for both her husband and her mother-in-law. Even with the help of relatives, Yang and her husband were barely able to put food on the table, much less afford pain medications prescribed for Chen's cancer. The cost of the small morphine patches was astronomical. The family simply could not afford them. Chen was forced to use these patches sparingly. He wore them four to five days at a time when they were only designed to last 72 hours at most. Eventually, Chen's family could not afford the medication at all. Now, with the hospice's help, Chen is able to live pain free and without agony. Without the hospice services, Chen said he would not have the strength to live. The pain management from these morphine patches, hospice counseling and support, Chen has since regained the will to live.

尽管有宁养院的支持和义工的帮助，陈先生一家仍是度日艰难。杨赛书需要照顾丈夫，婆婆还有两个儿子。现在，杨赛书的老父亲也需要她照顾，她又得喂多一张嘴，照顾多一个人。两个9岁和

13岁的儿子也一夜之间被逼长大。当9岁的小儿子看到妈妈所承受的压力和重担时，他总是在妈妈旁边安慰她，当妈妈不吃饭的时候，他也不吃饭。他每天晚上都为爸爸按摩双脚，减轻由于癌症所引发的水肿。13岁的大儿子尽自己最大的能力帮妈妈做家务，减轻妈妈的担子。开始的时候，杨赛书每次去宁养院拿药都忍不住痛哭流涕，把所有在家里捂得紧紧的焦虑释放出来。在接受了宁养院的辅导之后，她学会了如何在丈夫面前表现自己的情感。虽然，陈先生的手足对于他们的状况深感同情，他们尽可能地给予经济支援，或者帮忙照顾病人，但毕竟他们的经济都不宽裕，而且都有自己的家要养。从没受过教育的杨赛书在窘迫的经济状况面前束手无策。这些不幸和重担几乎让杨赛书透不过气来。

However, even with the constant support of the hospice workers and volunteers, getting through each day is still posing tremendous challenges for the family. Yang must care for her husband, his mother, and their two children. Lately, Yang's old father must rely on her as well. Now she has an extra mouth to feed and another person to take care of. Her two sons, nine and thirteen years old, are forced to grow up quickly. When the nine-year-old son saw his mother stressed out or upset, he would sit by her and comfort her. When she refused to eat, he refused to eat as well. Every night, he massaged his father's feet to relieve the edema caused by the cancer. The elder son did his best to ease his mother's burdens by helping with house chores. In the beginning, Yang would break down in tears during every trip to the hospice unit for the pain medications. With the hospice counseling, Yang had since learned how to cope with her emotion before her husband. Now she never cries or voices any unnecessary complaints to him. While Chen's siblings are sympathetic to Yang's troubles and offered money and aid when possible, none of them are well off. They are responsible for supporting their own families. Yang never received a proper education. She does not know how to deal with the many financial issues that now plague the family. These ill-fated circumstances and compounding burdens became too much for Sai-shu Yang to bear.

当被问到这样的劳苦和担忧是否让她很累的时候，杨赛书虽然眼泪忍不住直流，但却还坚定地说：“只要看到老公开心，好起来，我再辛苦也不怕。”她的眼泪并不是因为自己的苦难而流，而是因为害怕失去丈夫，同时也是因为对宁养院工作人员和所有帮助过他们的人无比感激之情而流的。宁养院对杨赛书一家的帮助让她深深感动。她毫无怨言地说：“我的命不好，可是还是有这么多姐妹帮我，我真的很感激。”她接着说：“我不识字，没读过书，也不会说话，不知道怎么谢谢宁养院。”她所能说的最能表达感激之情的就是：“他们就像我的亲生父母一样。”让杨赛书流泪水的部分原因是她非常害怕失去丈夫，害怕她的孩子在学校被同学称为：“没爸的孩子”。

When asked if she felt weary of the toiling in harsh conditions, Yang although tearful, declared firmly that any amount of suffering was worthwhile if her husband could get better and be happy. She did not cry out of frustration or personal hardships, but for fear of losing her husband and out of her tremendous gratitude for the hospice caregivers. Yang was deeply moved by all that the hospice staff had done for her family. Without a trace of bitterness and a single complaint, Yang said her fate may not be a fortunate one, however, she was eternally grateful to those who helped her. She added it was only because of her illiteracy that she could not properly put her thankfulness into words. She feels incredibly indebted to the hospice unit. The hospice staffs were like parents to her. This description of their relationship is the best way to illustrate how much the hospice staff meant to her. Yang also cried because she was terrified at the thought of losing her husband and did not want her children to be labeled as “fatherless kids” at school.

安慰
Comforting

陈先生及其家人只是众多接受宁养服务的一家，对这些贫困，不幸的家庭来说这份礼物是如此丰厚。当看到年轻的宁养工作者李敏拥抱着哭泣的杨赛书安慰支持她的时候，我们意识到宁养院最重要的服务不是给药，不是提供专业知识，也不是伸出帮助的双手，而是一份奇妙的爱和关怀。

Chen's family is one of the many to receive medical services offered by the hospice unit. For the impoverished and unfortunate families, these services are a gift. However, when one sees Li Min, a young hospice worker, and Sai-shu Yang in a tearful embrace, exchanging heartfelt words of support, one realizes that the most important thing that the hospice service can offer is not medicine, expertise, or even a pair of helping hands. Rather, it is the gifts of compassion and love.

图文：童心/林思妤 By Laura Tong/Lillian Lin

有一天你若真的失去勇气，
有一天你若真的想放弃，
有一天你若感觉没人爱你，
有一天好像走到谷底；

*One day if you are deprived of courage,
One day if you are going to give up,
One day if you are not feeling loved,
And it seems like you've hit a low;*

那一天你要振作你的心情，
那一天你要珍惜你自己，
那一天不要忘记有人爱你，
那一天不要轻易说放弃...

*That day, cheer up,
And cherish yourself,
Don't forget that you are loved,
And never give up...*

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